

UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND
REHABILITATION SERVICES ADMINISTRATION
REHABILITATION SERVICES ADMINISTRATION
WASHINGTON, D.C. 20202

INFORMATION MEMORANDUM

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ADDRESSEES: STATE VOCATIONAL REHABILITATION AGENCIES (GENERAL)
STATE VOCATIONAL REHABILITATION AGENCIES (BLIND)
STATEWIDE INDEPENDENT LIVING COUNCILS
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REGIONAL REHABILITATION CONTINUING EDUCATION
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AMERICAN INDIAN VOCATIONAL REHABILITATION
PROGRAMS
RSA SENIOR MANAGEMENT TEAM

SUBJECT: Multiple Chemical Sensitivity

CONTENT: In order to help RSA grantees and other service providers better understand and address the needs of persons with Multiple Chemical Sensitivity (MCS), RSA is distributing the attached document developed by the Arizona Technology Access Program, Institute for Human Development, Northern Arizona University. This document contains information on symptoms associated with MCS, potential causes of MCS, and suggestions on ways to accommodate individuals with MCS. The document also contains a listing of resources on MCS for consumers and professionals.

If you have any questions regarding this IM, please contact Dr. Thomas E. Finch at (202) 205-8292, or via email at tom.finch@ed.gov.

Joanne Wilson
Commissioner

Attachment

cc: NATIONAL COUNCIL ON INDEPENDENT LIVING
COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION
NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS
NATIONAL REHABILITATION FACILITIES COALITION
NATIONAL ORGANIZATION OF REHABILITATION PARTNERS

Multiple Chemical Sensitivity

Chemical-based products are all around: in the clothes we wear, in the food we eat and in the air we breathe. It is not possible to escape exposure. Many people have become sensitized to the chemicals around them. It is estimated that as much as 15% of the population has become sensitized to common household and commercial products.

For some people the sensitization is not too serious a problem. They may have what appears to be a minor "allergy" to one or more chemicals. Other people are much more seriously affected. Such people have a condition known as Multiple Chemical Sensitivity or MCS.

What is Multiple Chemical Sensitivity?

MCS is a disorder triggered by exposures to chemicals in the environment. Individuals with MCS can have symptoms from chemical exposures at concentrations far below the levels tolerated by most people. Symptoms typically occur in more than one area in the body, such as the nervous system and the lungs. Exposure may be from the air, from food or water, or through skin contact. The symptoms may come and go with exposures, though some individuals may have delayed reactions. As MCS gets worse, reactions become more severe and increasingly chronic, often significantly affecting bodily functions.

In the early stages, repeated exposure to the substance or substances that caused the initial health effects provokes a reaction. After a time, it takes less exposure to cause symptoms. An increasing number of chemical products may trigger a reaction, including some unrelated to the initial exposure.

Most frequently, MCS affects an individual's overall physical and emotional health. It typically impairs the nervous system. It may affect the digestive and respiratory systems as well. A chemically sensitive person may also have other pre-existing health conditions. Many affected people experience a number of symptoms with each chemical exposure.

Symptoms of MCS

- asthma or other breathing problems
- autoimmune disorders
- behavioral problems
- bloating or other intestinal problems
- cardiovascular irregularities
- chronic exhaustion
- disorientation or becoming "lost"
- dizziness
- dystonia (paralysis)
- ear, nose and throat problems
- fatigue and depression
- flu-like symptoms
- food allergies and intolerances
- genitourinary problems

MCS may result from a single massive exposure to one or more toxic substance or repeated exposures to low doses. Some people become chemically sensitive following a toxic chemical spill at work or in their community, or after exposure to pesticides. Or, individuals may develop

this condition from spending time in a poorly ventilated building, where they breathe a combination of chemicals. MCS may be brought on by a wide array of chemicals found at home, at work, in hospitals, in parks, and at school.

People Diagnosed with MCS

Studies have found that many people diagnosed with MCS were:

- industrial workers
- teachers, students, office and health care workers in sealed buildings
- chemical accident survivors
- people living near toxic waste sites
- people whose air or water is highly polluted
- people exposed to various chemicals in consumer products, food, and pharmaceuticals
- Gulf War and Vietnam Conflict veterans
-

Not all people with MCS fit into these categories. For example, some have experienced a toxic exposure from flea and roach sprays, or from foam insulation (urea formaldehyde) in their home. Other people with MCS cannot readily identify situations where they have been exposed to chemical products.

People with MCS may become partially or totally disabled for several years or for life. They must make fundamental changes in lifestyle and at home. Their marriages and other relationships may end from the stress of coping with this disabling condition. They may drag themselves to work only to return home sicker and more exhausted each day. They may be forced to leave their jobs and deal with the devastating loss of income and health insurance. Some people eventually recover, but few return to complete health.

What Can Cause MCS?

No one knows for sure what causes MCS. However, in non-industrial workplaces, a number of common products and processes have been identified as contributing to the onset of MCS. Some exposures that have been linked to this condition are:

- Agent Orange for Vietnam Veterans
- antibiotics and other medication
- carbonless paper, inks, copying machine and laser printer toner
- cleaning supplies
- DEET - an insect repellent which may have been a significant trigger for Gulf War Veterans
- formaldehyde in new clothes, books, and other products
- gas stoves
- house paints
- insecticides, synergists, piperonal butoxide
- new building materials and furnishings
- off gassing of new carpets (styrene butadiene latex in flooring adhesives and carpet backing)
- pesticides and wood preservatives
- second-hand tobacco smoke
- toxic chemicals used in art, photography, printing, etc.

- vehicle exhaust fumes

These substances contribute to indoor air pollution and are often contaminants in our air and water. Many of the chemicals that trigger MCS symptoms are known to be irritants or to be toxic to the nervous system. One especially harmful group of chemicals, known as "volatile organics," readily evaporates into the air at room temperature. Even low airborne levels of such contaminants can make ordinary people sick. The impact on health of long-term, low level exposure to most chemicals found in consumer products remains untested. The products and other chemicals that cause problems varies among affected individuals.

Commonly reported triggers include:

- anesthesia
- artificial colors, flavors, and preservatives in foods, drinks, and drugs
- detergents and other cleaners
- electromagnetic fields
- fluorescent lights
- perfumes and fragrances
- prescribed medications
- smoke from tobacco products
- solvents from dry cleaning, felt pens, etc.

When our bodies are assaulted with levels of toxic chemicals that cannot be safely processed, many of us become ill. For some, the outcome could be cancer or reproductive damage. Others may become hypersensitive or develop other chronic disorders, while some people may not experience any noticeable health effects. Even when high levels of exposure occur, only a small percentage of people become chemically sensitive. The threshold of toxic injury is not the same for everyone because the ability to detoxify varies greatly from individual to individual.

Treatments

MCS can be difficult for physicians to define and diagnose. Physicians should take a complete patient history, which includes environmental and occupational exposures, carefully test for familial or exposure-related tendencies like porphyria, use brain and brain function scans, and act as diligent detectives in diagnosing this condition. After the onset of MCS, a person's health generally continues to deteriorate. It may only begin to improve once the chemical sensitivity condition is uncovered. While a number of treatments may help improve the health of some patients, there is currently no "cure." In almost all cases, avoidance of exposures must be practiced to alleviate symptoms. No single test for MCS currently exists.

Avoiding the exposures that may trigger reactions is essential, and may permit dramatic improvement. Yet the large number of new and untested synthetic chemicals we encounter in our daily lives makes this extremely difficult.

Individuals affected by MCS have created "sanctuaries" relatively free from chemical emissions and electromagnetic fields in their homes. Because of the serious impact of even an accidental unavoidable exposure, people often spend as much time at home as possible and often cannot participate fully in society. As a result, they may experience intense isolation, loss of self-esteem,

and depression from not being able to have an active work, family, or social life. Supportive professional and peer counseling can help if available.

MCS and the Medical Community

Many conventional allergists and other physicians claim that there is not yet sufficient evidence that MCS "exists". Research regarding the mechanisms that cause MCS has been inadequate, and unfortunately is often financed by the industries, which benefit from chemical proliferation. Generally, medical doctors have not been trained to understand or seriously investigate conditions such as MCS. In fact, the vast majority of physicians receive very little training (four hours or less) in occupational and environmental medicine or in toxicology and nutrition.

Therefore, many affected individuals have to consult with a large number of specialists. People with MCS are sometimes misdiagnosed with serious degenerative diseases. Often, baffled doctors tell patients that their illness is psychosomatic...in their head. And many whose health is impaired by MCS have never heard of the condition. The lack of support from physicians, and the stress caused by having no explanation for symptoms, may contribute to a high level of anxiety and distress for people with MCS.

Conventional medicine offers very few medical treatments for MCS besides avoiding offending products. Unfortunately, medications and other conventional medical treatments offer little or no relief, and may even prompt new sets of symptoms. Treatment with anti-depressants may mask the underlying condition and can also cause other serious health problems.

Physicians who clearly recognize MCS include some occupational and environmental health specialists. A wide range of new or "alternative" treatments have been utilized by people with MCS with varying success. Some of these treatments are experimental and may include a combination of: nutritional programs, immunotherapy vaccines, food-allergy testing, detoxification regimens through exercise and saunas, chelation for heavy metals, and other healing treatments. Diagnosis may involve laboratory tests for chemical contaminants, such as total body burden of pesticides, or for porphyria, respiratory and brain function.

Unfortunately, these treatments and diagnostic workups are not often reimbursed by insurance plans. Few practitioners or medical insurance programs for people who are indigent support these alternative, yet sometimes productive approaches. Some disabled workers have won reimbursement for such care through Workers Compensation claims.

MCS Is Now Recognized as a Disability

Both the US Department of Housing and Urban Development (HUD) and the Social Security Administration (SSA) have recognized MCS as a disabling condition. People with MCS have won several Workers Compensation cases. A recent human rights lawsuit in Pennsylvania established the right of an affected person to safe living space in subsidized housing. Both the Maryland State Legislature and New Jersey State Department of Health have commissioned studies of MCS. The NJ study provides an excellent overview of medical and legal issues related to MCS.

Just as physical barriers prevent wheelchair access, chemical use can prevent entry and use of public facilities to those with MCS. The Americans with Disabilities Act (ADA) protects people with disabilities from many types of discrimination, requiring reasonable accommodation for people with disabilities. Reasonable accommodations can enable people with MCS to enjoy access to work, public facilities and other settings. Whether an individual developed MCS at work or was already sensitized prior to employment, the right to a safe workplace must be established.

Injured workers who need Workers Compensation or Social Security Disability benefits should find a physician who can diagnose MCS and who will support legitimate claims. Establishing clear documentation is critical in awarding such a claim, as well as for gaining reasonable accommodation at work or for rental housing. If your employer is discriminating, do the following:

- get your condition diagnosed
- if you work in a unionized workplace, consult with your union about filing a grievance or taking legal action
- seek legal counsel
- join a support group

For further assistance, contact a worker health resource group or support group in your area, as well as other organizations listed at the end of this fact sheet. These cases can be difficult and take a long time, but can be resolved.

Similarly, if you have been injured on the job, find an attorney experienced with chemical exposure cases in the Workers Compensation system or personal injury claims. You will not need to pay your attorney up front. Your attorney receives a percentage from the settlement if you win. It typically costs you nothing if your case is unsuccessful. To find an attorney, consult your union or one of the organizations listed below to obtain referrals. Select your attorney carefully. Remember, you should trust and feel comfortable with him or her.

Accommodating Individuals with MCS in the Workplace

These are some suggested ways to accommodate individuals with MCS at work. While not adequate in all cases, these measures will help prevent other workers from becoming similarly disabled, and contribute to the creation of a healthier work environment.

- windows that open to permit fresh air to circulate
- well ventilated space free of pollutants such as tobacco smoke, pesticides, toxic and fragrance-laden cleaning products, deodorizers
- selection of least toxic/allergenic building furnishings, flooring and supplies
- "least toxic" integrated pest management (IPM) using no sprayed or volatile pesticides in or around buildings
- pre-notification prior to painting, pesticide applications, and renovations, with provisions for alternative work arrangements
- education of co-workers, management, and other employers to avert stigma and harassment
- scheduling which permits people with MCS to work when fewer co-workers are present, when ventilation is at its peak, or where the work environment is least problematic

- allowing the option of working at home or off site
- minimizing exposure to electromagnetic fields from computers, fluorescent light ballasts, and other equipment

MCS Is Preventable

People with MCS are a driving force for improved indoor air quality and for the adoption of less toxic housekeeping and building maintenance practices. Good indoor air quality and substitution of less toxic materials boost morale and productivity. A healthy workplace lowers absenteeism and injuries. Complaints about indoor air problems must be taken seriously by employers, labor unions, regulatory agencies, and health care and social service providers.

For Help and Information

National Center for Environmental Health Strategies (NCEHS)

(609) 429-5358

Mary Lamielle, Director

1100 Rural Avenue

Voorhees, NJ 08043

Provides information, referral, and advocacy. Tracks scientific, legislative, legal, medical, and policy issues. Twice yearly newsletter, "The Delicate Balance." Information packets.

NY Coalition for Alternative Pesticides (NYCAP)

(518) 426-8246

P.O. Box 6005

Albany, NY 12206-0005

Focuses on pesticide hazards and safer alternatives. Provides information, referral, workshops, and advocacy "NYCAP News" is its 40 page quarterly newsletter. Incident reporting project.

MCS Referral and Resources, Inc.

Albert Donnay

508 Westgate Rd., Baltimore, MD 21229-2343

(410) 362-6400 Voice (410) 362-6401 Fax

Initiated by Grace Ziem, MD, DPH, to assist people with MCS, physicians, attorneys, and other professionals. Distributes articles and resources on prevention, diagnosis, accommodation.

Contact Albert Donnay online at: donnaya@r.tk.net or visit their homepage at www.mcsrr.org.

The Environmental Health Network

(415) 541-5075

P.O. Box 1155

Larkspur, CA 94977

Newsletter, "The New Reactor", MCS advocacy and survival primer, "The Good Old New Reactor," by Susan Molloy, is available for \$8.95 plus s/h.

Chemical Injury Information Network

(406) 457-2255

Cynthia Wilson, Director

P.O. Box 301

White Sulphur Springs, MT 59645

"Our Toxic Times: monthly newsletter

Center for Safety in the Arts

(212) 227-6220

5 Beekman Street, Suite 820

New York, NY 10038

Provides information, referral, workshops, and fact sheets on art hazards, safer substitutes and practices.

National Coalition for the Chemically Injured

(520) 536-4625

Susan Molloy, contact person in Arizona

Ste.C-501 HC-63 Box 7195

Snowflake, AZ 85937

National Office of NCCI

2400 Virginia Ave., NW

Washington, DC 10034

The Labor Institute

(212) 674-3322

853 Broadway, Room 2014

New York, NY 10012

Produced "Multiple Chemical Sensitivity: An Emerging Occupational Hazard" (28 minute video), and "Multiple Chemical Sensitivity at Work: A Training Workbook for Working People," (95 Pages). Order from APEX Press, Publication Office, P.O. Box 337, Croton-on-Hudson, NY 10952. (914) 271-6500.

Human Ecology Action League (HEAL) of Southern Arizona

(520) 577-9673

6655 E. Placita Alhaja

Tucson, AZ 85715-1251

The Dispossessed Project

(520) 636-2802

Rhonda Zwillinger

P.O. Box 402

Paulden, AZ 86334-0402

Graphically depicts the plight of people injured by toxic chemical exposure and who live with Multiple Chemical Sensitivities, through a collection of black and white photographs and biographical anecdotes. Provides a forum for people with MCS where they can accurately describe how they have lost their health and dignity.

Electrical Sensitivity Network

(520) 778-4637

Lucinda Grant, Director

P.O. Box 86302

Prescott, AZ 86302

Bi-monthly "Electrical Sensitivity News".

American Academy of Environmental Medicine

(215) 862-4544

10 E. Randolph St.

New Hope, PA 18938

Professional association of environmental and occupational physicians. Provides regional listings of member doctors.

American Indian Environmental Illness Foundation

(360) 665-3913

Terri Hansen, Director

P.O. Box 1039

Long Beach, WA 98631

Government Agencies

US Social Security Administration

Check your phone book under US Government Offices, Health and Human Services.

For general information, call 1-800-772-1213.

US Department of Housing and Urban Development (HUD)

Office of Fair Housing and Equal Opportunity

(602) 379-4461.

Request the MCS Information Packet, which includes citations and descriptions of helpful recent legal decisions regarding safe housing.

Additional Reading

Staying Well in a Toxic World: Understanding Environmental Illness, Multiple Chemical Sensitivities, Chemical Injuries, and Sick Building Syndrome.

By Lynn Lawson (1993)

\$18.95

P.O. Box 1732

Evanston, IL 60201

Neurobiology of MCS.

An interview by Cindy Duehring with Donald Dudley, M.D., Neuroscientist and President of the Washington Institute of Neurosciences in Gig Harbor, Washington.

April 1996 Issue of "Our Toxic Times."

Chemical Injury Information Network

P.O. Box 301

White Sulphur Springs, MT 59645.

*** Special thanks to Susan Molloy for her assistance in the creation of this fact sheet.

*** Portions of this fact sheet were reprinted with permission of the Multiple Chemical Sensitivity in the Workplace Task Force, NY Coalition for Alternatives to Pesticides, 353 Hamilton Street, Albany, NY 12210, (518) 426-8246.

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